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ABSTRACT

This paper addresses the need for a working partnership between the formal social service system and information network systems in light of decreasing resources and increasing needs of clients. The development of the Community Service Society Natural Supports Program (NSP), a project providing services to families caring for frail older relatives in their homes, is discussed before the two outcomes of this project are detailed. The first outcome is described as the formation of a Caregivers Network, a group of informal caregivers who contacted NSP for concrete services, became involved in peer support, and then moved to social action. A parallel development towards social action which occurred among the formal service providers and resulted in the formation of a social action coalition is also presented. The partnership of this social action coalition with the Caregivers Network is focused on through an explanation of the dependency of this partnership upon mutual goals, a recognition of each other's strengths and skills, and a need for the services of each other to attain goals. The materials emphasize that, under these conditions, a partnership can exist in which both systems rely on each other for strength and validation and retain separate identities and roles. (Author/NRB)

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A PARTNERSHIP OF CARING:
A BLUEPRINT FOR SOCIAL ACTION

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A Partnership of Caring

A Blueprint for Social Action

The future of social service in the 1980's appears bleak. Decreasing resources and increasing needs suggest that social workers will need to be creative and adventurous in seeking effective means of social action. One such means hinges on the recognition of the informal network systems among consumers of social service and the development of a partnership for social action between the formal service system and these informal networks.

In the past it has generally been the practice to view the informal and the formal networks in an adversary role. Formal service personnel have suggested that consumer self-help groups lack knowledge, professional ability or skills and, perhaps pose a threat to the credibility of the professional role. In turn the consumers have tended to form coalitions in defense against the"over bureaucratized" social service system, accusing the trained worker of incompetence and lack of feeling and of hiding behind the jargon of social work terminology. Gussow and Tracy suggest that such groups in their formation represent "a substantial consumer response to a basic inadequacy in the classical (medical) care system....."(1) Existence of these client/consumer groups alongside the formal service systems is often perilous.

At best, consumers would agree with Alfred Katz when, in referring to self-help groups, he suggests that "the greatest danger is that of co-optation of the groups by professionals which would defeat the groups' purpose and destroy their distinctive character." (2)

1. Gussow Z. Tracy GS: "Voluntary Self Help health organizations: A study in human support systems." New Orleans. June 1972.

2. Alfred H. Katz: " Self Help Groups" Encyclopedia of Social Work, 17th ed. Vol. 2. Washington, D.C. 1977.

The social and econmonic climate can no longer afford us this adversary role. Collaboration is necessary for advocacy on behalf of improved and increased services to meet clients needs. Means of forging effective partnerships for social action, in which the formal and informal networks are separate but equal, must be found. In observing the growth of one such informal network and its relationship to the social service professionals, three conditions for a"successful" development of such a partnership appear necessary. These are:

1. Mutual goals
2. Recognition and respect of each other's specific strengths and skills.
3. Mutual need for each other's skills and services in order to attain the desired goals.

Development of a Consumer's Social Action group

The Community Service Society[3] Natural Supports Program was inititated in 1976 as a research demonstration project providing individual service to families caring for frail older relatives in their homes. Three years later additional group services were provided, funded under a grant from the Administration on Aging.[4] The program grew out of the belief that families provide an enormous amount of care to their frail elderly, enabling them to remain at home in their own communities. Further it was believed that the act of caring may result in severe pressures-financial, practical and emotional - and that the provision of some formal services can help in alleviating these pressures. At no time were the formal services to act as subtitutes to the informal services being provided. The services offered - homecare, respite, education, skill training, counseling and peer support - were designed to ease the tensions of providing care, thereby strenthening the caregivers and allowing them to continue in their caring role.

3. Founded in 1848, the Community Service Society of New York is one of the largest non profit,non sectarian social service agencies in the U.S.

4. The program was funded in part by a grant #02-AM4802 from the Model Projects on Aging, AoA, U.S. Dept. of Health and Human Services.

Caregivers, both relatives and neighbors of frail elderly persons, entered the N.S.P. program in search of concrete services - homecare, entitlement advocacy, counseling. Once these immediate needs were met, caregivers tended to remain involved with group services because of the peer support and mutual aid they received from others in similar situations.[5] For many there was then a third stage, that of social action. A pattern began to emerge. First came the inner-directed search for concrete services to meet immediate needs, followed by an involvement in peer support, leading to an outer-directed desire for social action. As one participant exclaimed "Talking is not enough we need to do something."

Out of this stated need, a small group of caregivers was convened for the purpose of forming a social action group. It is the development of this "Caregivers Network" and its relationship to the formal service network that is of interest here.

The"Caregivers Network"has followed a pattern of development remarkably similar to that followed by the individual caregivers in their relationship to the program. For the first few months of its existence, the "Network", numbering approximately 8 persons, met monthly and discussed its purpose. There remained uncertainty as to its abilities, functions and role in the minds of the members who expressed ambivalence as to their ability to alter an existing system or even as to what specific changes they should seek. Interested in "empowering the natural supports" as advocated by Rep. Biaggi[6] the staff facilitator, sought to educate the members. The Network met with experts in the fields of entitlements, home care and lobbying. Armed with agreement as to the areas of deepest concern to them - homecare, transportation, financial aid - the members then entered a period of examining how they could best affect change. A negative aspect to the group's development at this time

5. Mellor, J. and Getzel, G. "Stress and Service Needs of those who Care for the Aged" presented at the 33rd Annual Scientific Meeting of the Gerontological Society. San Diego, Nov. 1980.

6. See "Future Direction for Aging Policy: A Human Service Model." Report by the sub committee on Human Services of the select committee on Aging, U.S. House of Reps,. 96th Congress. June 1980 U.S. Gov't Printing Office.

was that the original membership appeared unable to attract new members. It was difficult to encourage new members to join as long as the "Network" was unable to point to any specific action, or even to explain itself, but yet the members felt it was impossible to take action without an influx of new members. " We can't do anything unless we have more people." It became the task of the staff facilitators, in the ensuing months, to develop action steps, encourage their fulfillment and infuse members with a belief in their collective power. Opportunities to testify before legislators occurred. Network members were encouraged to participate and their activities widely publicised in the Network newsletter. This all served to confirm the group's effectiveness. A major developmental step occured approximately one year after the group's formation, when 4 members accompanied by 2 staff persons, travelled to Washington, D.C. to testify before the U.S. House of Representatives Select Committee on Aging. Only 1 staff member and 1 network member had the opportunity to speak out publicly, however all 4 Network members were able to meet with the Committee chairperson, Senator Claude Pepper, and the day, filled with shared travelling hours, a lengthy late lunch and the excitement of accomplishment, served to unite staff and caregivers in a common purpose. This sense of accomplishment carried over to the weeks ahead and inspired the total Network membership with a sense of direction. " We gave Washington something to think about and, do you know, Senator Pepper agreed with what we said."

Education, shared peer experience and then social action. Indeed, at this point the Network was able to participate in a variety of social action missions ie: letter writing, lobbying at the State Capitol, testifying at mini White House Conferences on Aging and outreach for new members. This period coincided with the award of a foundation grant which provided for the hiring of a part-time staff person to work solely with the Network. This, as well as allowing greater staff facilitation bestowed a sense of acceptance and self-worth upon the members.

Two years after its inception, by June 1981 the Network members felt strong enough to plan and host an annual reception for caregivers. Hitherto, this had been the province of the N.S.P. staff. At this time, too, the Network moved towards formal organization with membership cards, a printed brochure and caregiver buttons - all visible proof of the Network's existence. In spite of the members earlier feeling that nothing could be accomplished without greater numbers, the number of active participants had increased only slightly during this period and yet a great deal had occurred. The accomplishments attracted "new" members and so, even as the service program, which had initially brought the members together, was terminating, the Network group began to expand. The original core of members was encouraged by the presence of newcomers and steps were taken to formalize the organization even further with sub committees, work groups and elected officials. These organizational steps were advocated and agreed upon by the members themselves.

Development of a Coalition of Service Providers for Social Action.

Simultaneously with the development of the Caregivers Network, there was a parallel development occurring among the formal service network. Initially N.S.P. staff were aware intheory of the role of caregivers and the stresses that could result but a period of education was necessary for staff to understand what caregiving really meant. It was the caregivers themselves who taught that though the lack of concrete service - homecare, transportation etc. - was a real hardship, the overwhelming stress factor was the loss of self-identity. In devoting time and energy to a frail older person, the caregiver loses perspective of his/her own self and lives " as if living someone elses life."

This can result in anger and frustration, consequent guilt and a further heightening of the lack of self-worth. " Do you think I could be accused of abuse? Sometimes I do get so worn down that I get angry and shout at her." Another aspect not initially emphasised by the professional social

workers was that the caregiver, in caring for a frail older person, is being faced with the reality of his/her own inevitable aging, possible extreme frailty and death. " What if I become senile too. My father has been senile since he was 60 and I'm already 58 years old." These aspects, so vividly portrayed and examined by the caregivers, were an education to staff who were learning while they simultaneously facilitated peer support groups and advised the Network in the area of social action.

The second or peer support stage was also experienced by the professional staff. In their role of providers of service to caregivers, they sought to examine the optimum methods of service and to use each other's strengths in their work. The small number of staff involved in the program allowed for a collegial atmosphere. Group workers conferred with caseworkers for direction and caseworkers turned to group outreach workers for linkage to community resources. This sharing of knowledge and mutual aid in solving work/practice situations was never formalized but became a distinct mode of operation within the staff group. Workers from other agencies interested in developing service for caregivers, reached out to the N.S.P. staff for advice and consultation. In social work terminology, this was called technical assistance but the type of aid that workers sought from each other around understanding each others problems closely resembled the peer support phase experienced by the Caregivers Network.

As with the Network member this technical assistance or peer support phase led the social service workers towards an expressed need for social action. With the realization at a city wide conference, that caregivers needs and those of their elderly are not met by the available services and with the further recognition that staff from several agencies were identifying the same gaps and deficiencies in services, came the stated desire to form a coalition for social action.

Consequently, for almost a year now, a number of social service workers, representatives from various agencies and organizations, have met on a regular basis for the same purposes as that of the Caregivers Network.[7]

Discussion

Formed for the same purpose and forged by the same experiences, neither the Caregivers Network nor the professional coalition, seek to join forces and unite in one action group, although collaboration is desired and experienced. Staff workers facilitating each group confer regularly with each other, exchanging helpful information as needed. Representatives from each action group attend each others meetings, providing a liasion. Members of the coalition alert the Network members to upcoming legislation and legislative hearings and provide opportunities for caregivers to speak out at seminars and workshops. The Network members, in turn, provide the coalition with living case histories to substantiate their cause. Members from each group join forces to participate in media interviews and letter writing campaigns. Each group, while benefiting from this close,even symbotic, relationship, is aware that its own effectiveness lies in maintaining a separate identity. A merging of the two groups could result in loss of power. The challenge lies in determining at what point effective collaboration is in danger of becoming co-optation of one group by the other.

The partnership described here between the formal service providers and the consumers, between the social action coalition and the Caregivers' Network, is still in the process of developing. However the growth of the partnership to this point can be attributed to the existence of the three conditions stated earlier.

Mutual Goals

Caregivers, consumers of existing services, and the formal service providers are agreed on the need for increased homecare, transportation, medical and respite services.

7. Hudis, Gutwill, Mellor, Jaffee ' Formal and Informal Caregivers of the Elderly: A Coalition Prototype " presented at First Annual Mtg. of N.E. Gerontological Soc. May 1981.

Each group also feels that public recognition of the caregiving constituency is necessary before further services will be made available. The Network members, is particular, were amazed while listening to testimony before legislators to hear'professionals' state the caregivers needs for home care and respite in their very own terms. This helped to validate their own feelings and statements. In turn the service providers, after examining the theoretical basis of caregivers' needs at a conference, were galvanized into specifying service objectives after hearing from caregivers themselves, describing their personal situtuations. Shared goals and realisation of this results in mutual respect for each others' activities, for testimony provided by the professional coalition hastens the Network's cause and letter writing campaigns by the Network members enhances the coalition's own statements.

Recognition and respect for each other's specific strengths and skills.

The partnership is maintained, in large part, because members of each group recognize and acknowlege the strengths of the other. The professional social worker is aware that only the caregiver can really understand the caregiving situation and can speak from a base of personal experience. The professional requires education by the caregiver. In return the caregiver recognises that the social worker possesses skills such as entitlement knowledge, knowledge of pertinent legislation and experience in writing and testifying on social welfare issues.

The Network can develop a newsletter for its members but it is the professional that has access to printing and mailing facilities thus enabling the Network to reach out to a greater number of people. The caregiver has experience, at the front line, of the problems that can exist when home care is deficient, while the professional holds knowledge of whom to involve in creative change.

Mutual need for each other's skills and services in order to attain the desired goals.

Closely allied to recognition and respect of each others' skills, is a mutual need for each others' strengths, expertise and services. Even prior to the formation of a social action group the Caregivers require services to allow them to participate

at even the most elementary level. Zimmer refers to an "enabling milieu" 8 provided by service providers by which is meant the availability of financial aid for homecare and transportation to allow the caregiver to attend meetings. Also included in these enabling services are entitlement advocacy, counseling and education - all of which may be useful to aid a caregiver in moving through the initial educational stage towards participation in social action.

Beyond these enabling services directed towards the individual consumer, the 'professional' service provider possessess skills and strenths needed by the Network as a organization. The'professional' facilitator provides meeting space and is available to help in drafting letters, researching issues and conveying information to Network members. The Network can turn to representatives of the formal service network for aid in presenting its position, for knowledge of opportunities to testify and for means of co-ordinating and organizing activities. The formal service network, involved in social action, requires much that can only be provided by the caregivers themselves. Their role in educating the professional has already been stressed. The caregivers, as an organization for social action, also possess a committment born of need, a veracity and effect which provides a grass roots impact for change. In order to present a vivid case before legislators, the professional needs caregivers to portray a personal experience. During one notable lobbying day at the State Capitol, a legislator listened politely to a number of social workers but it was the consumer caregiver, speaking from experience who drew the greatest reaction - applause from the social workers and response from the legislator who went on to sponsor a pertinent bill in the next legislative session.

The Caregivers Network needs the professional social worker to provide staff functions and to set its needs into the wider framework of social services, while the coalition of providers needs the caregiver to provide realism and credibility

Summary

Shared goals, respect for each other and mutual need for each other strengths

8. Zimmer, A. "Advocacy for the Aged and their Families. The Balance of Informal and Formal Supports" presented at National Conference on Aging. Nashville, Tenn. April 1980.

and skills provide a climate for the development of a partnership. The partnership described here, though still developing, is predicated upon these conditions and as long as these conditions continue to exist, the partnership between the formal and the informal networks for social action is likely to continue and its chances of success in meeting the objectives will be maximised.

Whether the objectives are finally accomplished or not, the two partners already provide a vital service for each other by validating each other's role. Recognition of the caregivers needs by the service providers is professional validation giving the caregivers a sense of constituency. In turn the professional service providers find justification and credibility through the caregiver/consumer validation of their efforts. In the final analysis perhaps it is this validation of each other that will contribute most to the endurance and effectiveness of the partnership.

November 5, 1981